NORD®
National Organization
for Rare Disorders

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January 22, 2021

The Honorable Missy Irvin
State Capitol Building
500 Woodlane Street, Suite 320
Little Rock, Arkansas 72201

Dear Senator Irvin,

On behalf of the 1-in-10 individuals in Arkansas with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) commends you for your leadership and willingness to sponsor legislation to establish a rare disease advisory council (RDAC) within the state.

Creating an RDAC will give rare disease patients a unified voice in Arkansas state government. Rare disease patients in Arkansas face unique challenges every day of their lives, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition to battling for fair insurance coverage of their treatment and care. The Arkansas Rare Disease Advisory Council would help address these issues by providing a forum for stakeholders across the state to analyze the needs of the rare community and make recommendations on how to improve public policy.

Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, and best practices for the care of those with rare diseases. It will also be tasked with creating a rare disease plan for the state and developing methods to publicize the profile of the social and economic burden of rare diseases to ensure health care providers are informed.

The RDAC represents enormous value to our organization and the communities we serve by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges. In addition, the RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Arkansas government decisionmakers with one community voice.

In creating this council, Arkansas would join sixteen other states (Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia) that have already enacted similar legislation in support of their rare disease community and proven that the RDAC can be an invaluable resource.

Senator Irvin, we thank you for introducing SB143 and appreciate your support on this important legislation that will give a voice to Arkansas residents living with a rare disease.

Sincerely,

Alyss Patel

Alyss Patel
State Policy Manager, Western Region
National Organization for Rare Disorders

Tammy Jones

Tammy Jones
Volunteer State Ambassador
Arkansas Rare Action Network